

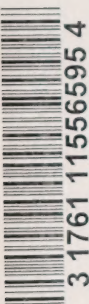


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All Together Now

How families are affected
by depression
and manic depression

Canada



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by depression
and manic depression**



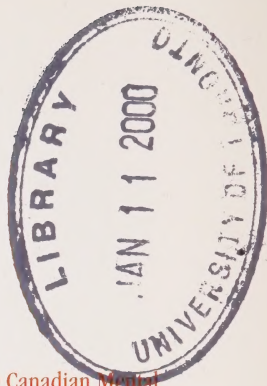
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Our mission is to help the people of Canada
maintain and improve their health.

Health Canada



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Contents

Introduction	7
Your Children	9
What Do Kids Say?	10
Dealing with Feelings — What Helps the Most	12
For Partners and Spouses	17
How Are You Doing?	17
What Partners Can Do	21
A Few Helpful Ideas	22
For the Patient	26
What's Happening to Me?	26
Coping Strategies	29
Accepting — and Assisting — Yourself	33
Getting Better — Treatment and Education	34
Treatment	34
Education	37
Resources	41
Books	45



Introduction

Depression and manic depression (sometimes known as affective disorders or mood disorders) are among the most common illnesses in our society, affecting more than 10 out of every 100 people. Although almost everyone will say, “I’m depressed,” from time to time, feeling sad or down is not the same as suffering from depression. Depression doesn’t go away in a few days and it’s not caused by a lack of willpower or personal weakness. Affective disorders are illnesses which can be diagnosed and treated successfully. We know a lot more about depression and manic depression than we did only a few years ago. And we’ve learned how deeply these disorders affect the whole family. That’s why this booklet was written: to help families live with affective disorders.

This booklet is based on the findings of a major research project involving people across the country — patients, partners, adult children who grew up with a depressed parent, and also the professionals who work with them. This study provided some very meaningful information about what it’s like for families to live with depression. The ideas in this booklet are based largely on what they told us about their feelings and the methods that helped them cope.

Some of these suggestions may be helpful in your family, or you may just feel better knowing that someone else understands what you’re going through. A list of places with more information has also been included for your benefit. We hope you’ll find something here that helps make life a little more comfortable for you and your family.

A note about language. This booklet is about depression and manic depression, but you will notice we have varied our terms. Sometimes, we say affective disorders which is an umbrella term for mental disorders like depression and manic depression (also called bipolar disorder). Terms like mood disorder, condition, illness and mental illness are used as well.

When we say patient or consumer, we're talking about the person with the disorder, and in general, when we say partner, we mean the adult without the illness. In some sections, we refer to the patient as he or him, in others we use she or her. However, all examples apply to both genders.



Your Children

Like every parent, you sometimes worry about your kids. In families affected by mood disorders, there may be additional questions:

- Will my children's development be harmed in some way?
- Are they at risk for developing the condition themselves?
- Is depression going to affect my relationship, or my partner's relationship, with my children?
- What can I do about it?

These are all worthwhile questions to ask. Because, in fact, children who grow up with a depressed parent do have a higher risk of certain kinds of problems both in childhood and later in life. The good news is that the likelihood or severity of these problems can be reduced — even eliminated — when families have the knowledge and support they need.

My wife and I are doing our best to keep our jobs and our lives together. I wish we were more skilled at looking after our kids and making sure they're cushioned from whatever genes and psychological stuff we're passing on to them. —ERIC

What Do Kids Say?

You may be wondering how your children feel. Though it's hard for them to tell you, research has given us some insight into how children feel when they have a parent with depression or manic depression.

What's going on here?

Sometimes, we assume kids don't need to know, or shouldn't know, or that they won't understand what's happening to their parent. But looking back, many children said they knew something wasn't right, they just weren't quite sure what the problem was.

There was tension in my family but we never talked about it, it was just sort of there. I knew my parents were having difficulties and it was affecting my brother and me but nobody really talked about it. **LESLIE**

I'm alone

Some adult children who grew up with a depressed parent say as kids they often felt alone within the family. In some cases, parents are so focused on the person who is not well and are trying so hard to cope with the overall situation that kids feel left out.

When my dad was sick the whole family had to group together and swing into action. We would take turns being with my dad and helping with household chores. It wasn't fun but somehow we had to do it. **BRIAN**

I have no say in this

Adult children often talk about feeling powerless as kids, about feeling unable to help their family's situation.

I remember feeling like I had no voice. I didn't know what was going on. I had no involvement in decisions — no power over what was happening. **GRACE**

I feel angry

Looking back, many adults who grew up with a depressive parent speak of the anger and sadness they have to deal with.

I guess I have had to come to terms with the anger I had about my mother's life and the fact that I felt shortchanged in some ways. I had to mourn the mother I wish I'd had. **KARLA**

It's my fault

Children often harbour a secret belief that they are somehow to blame for their parent's illness.

When things began to change in our family when my dad got sick, I thought it was because of me, that everyone was upset because of me. **ROB**

Why can't I just be a kid?

When a parent is in a depressive period, children sometimes take on adult-like roles and responsibilities. Whether this happens out of necessity or out of a sincere desire to help, many children are left feeling distanced from their peers.

When dad was sick, my mother would sometimes work two jobs. My older sister had to babysit so she used to get pretty sick of us being around. She was almost like a parent who was too young to be one. **FRANCES**

Will this happen to me, too?

Some children worry they themselves may become mentally ill. They might think they will inherit or even “catch” their parent’s disorder.

I try not to think about depression in my family, but it's always there in the back of my mind. And yes, I worry about the possibility of depression affecting me. MEAGAN

What's the matter with us?

We’re all aware of the stigma surrounding mental illness. Children feel it, too.

I guess the teens were the toughest because that's when you want to be normal. I explained to a lot of people that my dad wasn't crazy, but that he had an illness. But they would still say, "Well, does he scare you? Is he going to try and kill you all?" I would get this type of thing and that used to really upset me. JESSE

Dealing with Feelings – What Helps the Most

When we think about our children’s feelings, several things become clear. Kids need information, they need their questions answered, they need gentle encouragement to talk about what they are experiencing and feeling, and, like anyone else, they need normal, happy childhood experiences as much as possible.

What helped me survive was being able to talk about how I felt. I was lucky to have a few close friends. I was able to share things with them. DONNA

What should I tell them? And when?

We love sharing information with our kids — everything from why the sky is blue, to how the world works. Depression, though, is not usually at the top of the list of items we're bursting to discuss.

However, just like adults, children will notice that something is amiss in their family and will try to make sense of it. The trouble is, the explanations kids come up with on their own may be incorrect. For example, they may think the situation is worse than it really is or that their parent does not love them anymore. So, while it may not be easy, it's important to keep children in the loop when a parent suffers from a mood disorder. There is information available to help them understand depression a bit better — the question is how much information and at what age?

There's no set answer to this, but there are a few general guidelines to keep in mind.

Give them the straight goods...

You'll have to find your own way to say it, but the basic message is this: daddy (or mommy) isn't feeling well. He feels very sad, it's because of an illness and it's not anybody's fault. It is a sad time for all of us, but I'm here to talk to you about it when you need to.

... One day at a time

While it's important to be up front with your child, there's no need to fill her head with too much information. It's a bit like answering the question, "Where do babies come from?" A three-year-old isn't looking for a complete course in human sexuality and reproduction.

Similarly, when talking about mental illness you can start with a few general ideas as suggested above and then follow your child's lead. Or ask: "Do you have any questions you want to ask me about that?" Let them tell you how much they need to know.

At times, children may prefer not to talk or think about it at all. It's wise to respect their wishes, and wait until they ask you for more information.

My sister managed by going out a lot. I was the one who stayed home but I had a special imaginary friend that I talked to for a number of years. So I just detached myself, that's how I coped. **DONNA**

Give them hope

Your child may wonder: "Is mommy or daddy ever going to get better?" Happily, you can say yes. We know that depression and manic depression are treatable and that most patients recover. Let your children know that the condition is being treated and mommy (or daddy) will feel better sometime.

When I was a teenager things at home were not good at all. I seemed to get the brunt of my mother's anger. Somehow though, I always managed to believe that things would get better, which they did. I never felt that it was my fault.

KARLA

Make sure they know you love them — no matter what

All children need unconditional love. Your kids may need to hear "I love you" a little more often. They need to be reassured that no matter what difficulties the family faces — or how that translates into time away from them — you and your partner never stop loving them.

I felt such strong, unconditional love from my dad and from my teachers. That gave me reassurance as a person. I knew I would be okay. **KARLA**

What Else Helps?

Supportive relationships outside the home

Any number of people can play a significant role in your child's life — a teacher, a coach, a brownie leader or a favourite aunt. The important thing to realize is that close relationships with caring adults outside the home can be very beneficial to both your children and yourself. If there's someone like this in your child's life, do what you can to nurture that relationship, it's good for everybody.

We had a family that lived underneath us and the mother took us under her wing. We were both avid readers and we would exchange books and talk about them and she would feed me and things like that. **DONNA**

Let kids be kids

Playing with friends, going skating or taking piano lessons are all important for children. At times, it might be easy to let these experiences go by the wayside, but remember, participating in these types of childhood activities can go a long way toward helping kids feel normal. If it's hard to find time to take your child to soccer games or brownies, perhaps a neighbour or family member can do it for you.


For me it was important to have a life outside the family. I was active in sports and I had friends who would invite me over. I was happy when I could be doing things with my friends. That kept me strong and made me feel like one of the group. **MARIA**

Good parent/child relationships

At any stage of childhood, a mood disorder is likely to have an impact on both parents' relationship with a child, and, as you might expect, younger children are somewhat more at risk. A number of children described the importance of positive parenting, both by the affected parent when they were well and the other parent at all times. If you are the well parent, your consistent good relationship with your child is obviously very important, but you can also play a role in helping your kids maintain a connection with your partner when he or she is ill.

When your partner is going through a depressive period, she is going to be less emotionally available to your child. But to keep them separated would be wrong. They need to interact, even if it's only for a brief period. Find one or two things that are short or simple to do together — watching a TV program, reading a story or cuddling at bedtime. Use your knowledge of both people to find an activity they can enjoy together.

When my mom was well, she was very loving. She would read to us, she played with us and she was there for us. The cleaning could wait and the kids were more important. That was very important to me. DONNA



For Partners and Spouses

How Are You Doing?

Was it something I said?

When something is bothering our spouse, we ask ourselves: "Did I do or say something to cause this?" Nobody is a perfect partner, but depression and manic depression have to do with more than how your marriage is going. Heredity, early experiences, life events, medical conditions and physiology are among the possible causes of depression. With bipolar disorder, heredity and physiology are thought to be the key factors. In other words, it's not your fault.

When my husband became depressed, I thought it was me. I thought I was demanding too much. I later learned otherwise, but in the early years I wondered what part I had played in his depression. JANICE

Wish I could make it better

It's natural and right for a loving partner to want to make everything okay again. But try not to get caught up in thinking everything will be

better if you just care for your partner in a certain way. The reality is, this condition is bigger than you. You can help, but you can't make it go away.

It's lonely at the top

Some partners have expressed feeling alone in their marriage. At times, they're responsible for trying to hold everything together and wish their spouses could somehow appreciate what living with a depressed person is like.

I would like a bit more recognition from him as to what I went through. He'll say, "But I was ill." But I was there, too! And at times it's been pretty lonely in this marriage. HELEN

I'm carrying a big load

Many spouses talk about being consumed by the demands of the illness. You may have to carry the responsibility when it comes to looking after the children, maintaining the home, putting meals on the table and making sure bills are paid. And while your spouse probably needs you to do that, you may wonder if you're becoming a control freak.

I always did the grocery shopping and the household planning but now almost every day she asks me what to plan for dinner. So now I'm controlling the daily menu. I'm basically controlling her in a lot of ways. Or I wonder if she might see it that way. Sometimes I get the feeling she's rebellious because of it. And I understand that. There are times when I try to give some of the control to her, but she can't really handle the responsibility. So I feel guilty at the same time as I feel that I have to take over. RON

What do I tell people?

We all worry about the stigma attached to mental illness. You might feel like you don't want anyone to know that someone in your family is suffering from depression or manic depression. While it is true that not everybody has to know, there may be some people who should be informed because of their close relationship with your family. And knowing might make it easier for them to be supportive. This is something you should discuss with your spouse. In the event that you don't agree, it is probably best to honour your partner's wishes.

At first we didn't tell anyone anything. We just didn't know what to say or how it would be perceived. I now wish that I could have been more comfortable in just saying, "She's suffering from depression." I think that would have helped both of us get support. GUY

What's next?

You probably don't need anyone to tell you that mood disorders can be unpredictable. As a result, partners are often unsure of what to expect from their spouse. You would like to be able to read your partner's mood to determine the best way to be supportive. But this can be tricky.

And you never know, because they withdraw into themselves and they don't tell you what they're feeling. You never know how to gauge their mood. So sometimes it's impossible to know what is the right thing to say and what is the wrong thing to say. FRED

When your partner is manic

Partners of people with manic depression have to deal with a different kind of unpredictability — the manic phase. Your partner may

suddenly have inflated self-esteem or feel little need for sleep. Additionally, you may find that his thoughts race and he talks a blue streak. These are all normal behaviours in a manic period. They may arrive suddenly, and stop just as suddenly.

During one of my husband's manic periods, he got it into his head that we had to have a pond, and it had to be right beside our swimming pool. Even though everyone but him could see that it was a bizarre and impractical idea, there was no way to talk him out of it. ANNETTE

Suicide

For many partners of people living with depression, the big worry is that the spouse will want to take their own life. We know that thoughts of suicide are one of the symptoms of depression.

She had accumulated a fair number of pills from when she was hospitalized. She made it known to me where the stash was, and I got rid of it. But really, it's impossible to make your house completely safe so that a person can't do herself in if she really intends to. I mean, I can't be watching her every minute. So when the mood is bad, you're constantly walking on eggshells. RON

If you believe your partner is suicidal, there are several sources of support available to you. Contact your family doctor, a local crisis line or your nearest mental health support agency.

What Partners Can Do

How can I help?

The good news is that there are a variety of ways you can help, starting with what you're already doing: looking after the house, caring for the kids, holding down a job. The effects of your efforts may seem insignificant at times but remember this: a little bit better is a lot better than nothing.

Spousal support

If there were an easy answer to this, somebody would have patented the idea and now be a millionaire. But supporting a spouse with a mood disorder is an imperfect science. Many factors are involved — your partner's personality, your personality and your living circumstances, to name a few. You'll probably always think you could manage life better. Spouses are constantly searching for the balance points — between encouraging and nagging; between accepting their partner's illness and being apathetic about it. It's not an easy role to fill.

Sometimes, I would be sympathetic and let him stay in bed. Other times, I would feel like shaking him and saying, "For God's sake, get up and get a life!" I have learned that neither approach works — it's a delicate balance — wanting to help but not always knowing the right thing to do. SHIRLEY

A Few Helpful Ideas

Treat your partner like an adult

A depressed person may seem like a helpless child at times and it's very easy to slip into the habit of treating him or her like one. But it's best to approach this situation as equals. One man made an agreement with his wife that when he noticed she was staying in bed a little longer, instead of scolding her he would simply bring it to her attention because they had both agreed it was a sign she was slipping.

I can no longer be his mother. It's better that we be two adults trying to solve the problem. **BETTY**

Know when to back off

Depressed people need our help and support, but they also need to take responsibility for their own circumstances. At times it's best to simply listen, and give your partner the message that you believe in time she can resolve the issue herself.

Sometimes I just have to let things alone, get on with taking care of things and hope that the medication will kick in. **PHIL**

Don't ignore problems

Working out difficulties in a relationship is seldom easy. When one partner is depressed, it can be even harder, but it's even more important to approach issues head on. You may avoid discussing a conflict because you think it may be a waste of time or because you don't want to upset your partner. But little problems can turn into big ones when they are left too long.

I think we have come to a good understanding that we must deal with issues when they come up. Don't let them build. We

seem to have worked out a way of sitting down and talking things out, but we needed help from a therapist to get to this.

ANDY

Stay positive

It's going to be hard for your partner to do this, so provide an example. Don't shower him with a steady stream of compliments but try to find a few positive things to say every day. Even small things like your partner helping with dinner should be acknowledged with a few simple words.

Sometimes, it's hard to stay up. One of the things that helps me is to remember the good times. We have some good times behind us and I need to remember them. **HAROLD**

Helping Yourself

You can't control what's going on with your partner's life now, but you still have some control over your own. Take the time to look after yourself during the difficult periods. It's good for you and it helps your partner, too, because you are in a better frame of mind to deal with other things.

The nurturer needs nurturing

When you spend a lot of your energy caring for someone else, it's easy to forget your own needs. You might think, "I'm not the one who's ill" or "The helper isn't supposed to need help." Well, you do need help, and it's okay to admit that.

It is so important for me to remember that I deserve time for myself, that I need my breaks, my time and my friends. I try to build that into my life even though it's hard to remember to do this at times. **MARTHA**

Helping out around the house

Some of the support you need may be practical, like help with household work or child care. A friend or relative may be willing to bring over the occasional casserole, or do some cleaning or babysitting. If you can afford it, some of these services can be purchased. This is not a frivolous expense if it helps your family cope. If you work for an organization with an employee assistance plan, you may qualify for home care. Check with your employer.

That's what friends are for

Many partners have said that having someone to talk to helped them cope. Some friends may be willing to offer support, but are uncertain about how to approach you. If you're feeling overwhelmed, don't be afraid to ask. If friends inquire, "How can I help?" offer a concrete suggestion: "I'd love a home-cooked meal sometime," "Let's watch a video together some night" or "Can you watch my kids while I go to the gym for a workout?"

It's essential for spouses to be supported. Whether it's a counsellor, psychiatrist or just friends, I don't know how I would manage without supports. LAURIE

Blocking out the bad times

There will be aspects of this experience you might wish to forget. You may or may not be able to do that, but some people feel that blocking out or setting aside some of the bad times helped them to move on in their relationship with their partner.

You know what? I don't even remember all the specifics. I think I've blocked most of it out. If he said to me, "What exactly did I do?" I'm not sure I could tell him. JOYCE

When all else fails... laugh

There will be many times when laughter is the furthest thing from your mind, but many people have found that retaining a sense of humour kept them from getting bogged down with their partner's condition.

The biggest thing that has helped me survive this mess is a sense of humour. Do not lose that ability to laugh, because some of these things that happen are idiotic in a way. JOYCE

A little knowledge is a good thing

One of the most useful tools for dealing with your partner's depression will be learning about it. Ask your doctor, your local branch of the Canadian Mental Health Association or Mood Disorders Association (a.k.a. Depression/Manic Depression Association) for information on current treatment, the latest research or new studies. Check your newspaper community listings for notices about support group meetings or find out what information about depression is available at your local library. Just remember that along with the clinical knowledge it's important to get information about living with mood disorders. The best comes from people who have gone through this experience themselves.

The great escape

Somedays you'll think you can't afford to take time for yourself. On other days, you'll feel you can't afford not to. Remember, even small things are helpful — a walk with your dog, a night at the movies with a friend. Don't forget about playing with your kids, too. Children are the experts at escaping from reality. If you ask, maybe they'll let you tag along for the ride.



For the Patient

What's Happening to Me?

If you are suffering from depression or manic depression, you don't need anyone to tell you the experience can be devastating. Along with feeling a sense of inadequacy or hopelessness, you may also experience some of the following emotions and situations.

Isolation

Many people say they feel alone in the world. They worry no one will want to know about their condition or that friends, family and co-workers may not understand what they're going through. Single parents may feel even more isolated.

When I developed depression and had some difficulty in my workplace, it was as if everyone was saying, "Oh God, don't touch her, don't touch her." They would look at me and act like, "I don't know what your problem is lady, but we have no problems in this workplace." And I would think, "Hello?" Like I'm screaming in the dark and you're turning your back and walking away. MARY

Uncertainty about what's normal

Some people living with depression say they feel cut off from the real world — disconnected and different from the people around them.

You don't have a reference of what normal is, as far as other people are concerned. So all through my teens, twenties and even into my thirties, people were saying to me, "Smile!" For a long time I just thought that's the way I am. JESSIE

Concern for family

You may worry about the effect of your depression on your partner and your children. At times, you might wonder if your illness will wear them out or if your relationships will survive.

I think it's very important, from my experience anyway, to have somebody who's there for you. But I worry that my partner might not be getting what she wants. I mean, she's not getting an equal partner, she has to carry the ball. I worry about how long she can take this. ANDREW

Why are my children acting like this?

Is your children's behaviour bothering you more than usual? Of course, their behaviour may change as a result of what is going on in the family, but many patients observe that they are more irritable than usual when they are depressed.

What was surprising to me is that when I was depressed I found that my children's behaviour would irritate me. However, when I was well the same behaviour would pass by me unnoticed. ANNA

Distrust from others

Affective disorders can be unpredictable. People have times when they feel well, and others when they don't and, as a result, they are not as available to their families. Even when things are going well, fear that the depression will come back may hang over the house like a black cloud.

There's just a lack of trust. They don't trust you to be a full partner. I think that spills over to your children, too. They just don't understand why you are the way you are and they can't trust you. **ANDREW**

Awkwardness/Embarrassment (about disclosing illness)

Most people suffering from a mood disorder are aware of a stigma attached to having any kind of mental illness. Sometimes, they attempt to disguise or hide their problem from outsiders.

My boy went to a private school, and if it ever got out that I had a mental illness, that would be the end as far as my wife and son would be concerned. **DAVE**

Some feel that their illness will not be accepted by people within the extended family.

My husband has never told his parents that I have depression and when we're with his parents, and I'm depressed, I just remove myself. He makes excuses, "She's not feeling well, she has a headache." It's not an acceptable illness in that family.

DYANNE

Sexual desire

Not surprisingly, people suffering from depression or manic depression often say they have a lack of sexual energy. They may not feel desirable, and some medications have the side effect of lowering sex drive. In a manic phase, they may have increased sexual energy.

When I am depressed the last thing on my mind is sex. When I'm high, I have had affairs that have nearly ruined my marriage. We are working on this now, but it's something I will always feel guilty about. I feel bad that I have not always been the partner I should have been. JERRY

Despondency

When we're in the middle of a crisis, it often feels like things have always been this way and always will be. When we're physically ill, it can be hard to envision the day when we will be better. During a depressive episode, it can be doubly hard. But there is hope. As we have said before, there are effective treatments for depression and almost all patients do feel better eventually.

My advice to people who are going through this is "Hang on." There are days when everything looks black and you can't see your way out. But slowly, slowly you will begin to feel better and when you do, you will look back in disbelief at where you were. SERENA

Coping Strategies

Treatment, therapy, information, education and support all play very important roles in helping people with mood disorders feel well again. Individuals have also mentioned a number of strategies they used to help them deal with depression or manic depression.

Coming to terms with your illness

Accepting that you have a mood disorder requires some time. Once you do come to terms with the fact that your condition is due to an illness and not a weakness of character, things may look differently. You might be less inclined to think that if you just tried a little harder to be happy, you wouldn't feel this way.

Each day, I try not to think too much about my past problems and future worries. I just say, "Hey, I don't feel good and maybe I'm not going to get done what I want to get done, but tomorrow is another day and I'm not there yet." JESSIE

Going public

It takes a great deal of strength to go public with your illness. However, people have found that confiding in someone they trust is an important part of accepting their condition.

When one of the local television stations asked to interview me about depression, I decided, "I need to do this. This is who I am right now, I'm not going to pretend differently." I actually got a lot of phone calls from people in my neighbourhood saying, "I saw you on TV and you were great." DYANNE

Silence is not golden

While it's true there is a stigma about mental illness, part of the problem lies in not talking about your depression. Friends may know something is wrong, but if you're silent about the cause, they will feel uncertain about how to act and may feel they have to keep a secret. Being open about your mood disorder is a way of giving people permission to be supportive. It gives them an opening to ask, "*How can I help?*" without invading your privacy.

Key connections

Almost all people who have lived with depression and manic depression speak of the importance of supportive relationships, of finding special friends who are prepared to listen without judging, who accept them no matter what.

Part of what I did was to get help for myself through various family members, talking to them, talking to people at the mood disorder association and seeing a counsellor. All of these relationships have helped me in different ways. PAT

Drinking and Depression Don't Mix

Understandably, some coping strategies are less productive than others — use of alcohol for example. Many patients have had to come to grips with the fact that they had been “self-medicating” with alcohol as a way to deal with depressive symptoms. While it may work temporarily, down the road it creates another problem — alcohol dependence.

After I was treated for alcoholism, I began to see more clearly the symptoms that I am now dealing with. I used alcohol to mask them for a great number of years: both the depression and the manic episodes.

JOHN

Coping at Work

How you deal with your illness at work will depend on the kind of work you do, and your relationship with your supervisor. You may find it difficult to keep up with your normal workload and you may worry about losing your job, but there are ways to deal with these concerns.

Discretionary disclosure

Nobody wants to stand up on a chair at work and say, “*Hi, everybody. I have an announcement to make. I have depression.*” However, some individuals have found it helpful to disclose their illness to a trusted worker or supervisor. Not only is it a way of accepting their illness, it also allows co-workers to be supportive when needed.

Seven years ago, my boss knew nothing about my illness, but I was close to this one person. Finally, one day, I said, “I’ve got to share something.” I told her that I’d been in the hospital with depression. It was a relief to her because she’d always suspected something. **MARILYN**

Workplace adjustments

Some employers may be willing to accommodate you with programs like flex time. If, for example, you have trouble getting up in the morning, working different hours — say 11 a.m. to 7 p.m. instead of 9 a.m. to 5 p.m. — may help you function more effectively. Colleagues may be able to offer less formal, but very real, support. And remember, some employee assistance plans cover counselling and other forms of treatment.

I had come back to work, and because of shock treatment, I had some memory loss. I was supposed to be the supervisor and I couldn't even remember how to turn the coffee machine on. I told my friend that I'd been in the hospital and that my memory was bad. I asked her to brief me on a few things and I made notes. **MARILYN**

Accepting – and Assisting – Yourself

There has been a lot of talk here about accepting your illness. However, it would be wrong to interpret that as meaning: "There's nothing I can do" or "I have no responsibility in this." In fact, you have a very real opportunity to help yourself, to make a positive difference in your life. The single most important thing you can do is seek help.

You need to learn to work with yourself, accept yourself, accept your faults and say: "No one is going to hold my hand and take care of this for me. I have to take ownership and live each day for what it is." **JESSIE**



Getting Better – Treatment and Education



Treatment

When someone in our family has a physical illness, we expect to be involved in their care. A little girl might take a drink to her father who is sick in bed with the flu. A woman who has breast cancer will discuss treatment options with her husband and physician. However, when it comes to mood disorders, it's not as straightforward. For one thing, not all professionals agree on the best course of treatment. Some will prefer medication while others favour psychotherapy. In fact, recent research has shown that for most people, a combination of medication and psychotherapy works best and the sooner people get treatment, the sooner they feel better. We also know that the new medications have fewer side effects.

Treatment challenges for families

Although therapies can be very effective, it's common for families to start off feeling somewhat bewildered as they enter the world of mental health treatment.

We initially started going to medical doctors because he had very severe headaches. Looking back, it was probably anxiety symptoms but we went running around from doctor to doctor and psychologist and psychiatrist. Sometimes, we felt like there were turf battles about who should be treating whom and whose territory is it? I wish there had been more cooperation and coordination of services. **MARILYN**

On the outside looking in

Family members often report feeling left out of the loop — not included in conferences, treatment planning and discharge planning when patients are hospitalized.

When my husband was in the hospital, I kept expecting to get involved in the process. I kept thinking they would get us involved in the treatment and some training, but nobody ever called me. **ROSE**

This can be very frustrating and worrying for those who will be living with and, in some cases, caring for a spouse or parent who may be in a very fragile mental state.

They will release a person in a delusional state, assume the person can fend for themselves. But they can't. So who does? The family. **BETTY**

Problems with confidentiality

Part of the difficulty is that when a person is being treated for any kind of mental illness, confidentiality becomes an issue. Psychiatrists and other professionals are sometimes reluctant to talk about treatment issues with family members because of this.

All I did was ask the psychiatrist how he felt my wife was doing. And he became angry with me. **CLAUDE**

Who will talk to me?

My son had just been admitted to hospital. It seemed like my whole world was falling apart and I couldn't find anyone who seemed willing to talk to me about what was going on with him. I sat in the clinic waiting room for hours waiting for a chance to speak with my son's psychiatrist. When he finally came out, he spoke to me while walking down a corridor without ever stopping to look at me. CHANTAL

Hopefully, not all conversations between family members and professionals are like this one. The psychiatrist in question may well have had a heavy caseload and was behind in his work that day. Part of the problem may be that while both consumers and professionals know that depression and manic depression affect the whole family, their experiences differ. Family members spend their time coping with the illness, trying to keep their lives together, while a professional's main job is to treat the individual. This is what the system pays them to do. They also have many patients to treat. As a result, professionals are not always able to address family issues the way they'd like to.

Putting Yourself Back in the Loop

If you're feeling left out of your partner's treatment, here are a few ways to help get back in the picture.

You have a right to ask questions

It may not always feel like you are being encouraged to do so, but you have a right to ask questions about the treatment of a family member. You may have to be persistent and you may not get answers to every question, but you're not wrong to ask. If you don't make inquiries, you have less chance of getting the information you need.

Remind professionals that depression is a family issue

Professionals know this. In fact, research suggests that many wish they had more time and support for working with families. However, their workload and orientation toward treatment of patients makes it difficult for them to make families of patients a priority. A polite and diplomatic reminder may be helpful.

Discuss your involvement with your spouse

You may assume your spouse wants your involvement in treatment decisions. However, one reason cited by doctors for not involving the family in treatment is that the patient requested it. It's very natural (and right) to want to help the person you love, but your partner may wish to keep things to herself for reasons you don't understand. In such cases, you have to be patient.

Don't give up

It may take some time to get a diagnosis and find the right caregiver, but many families have reported that they eventually found a health care provider (family doctor, psychiatrist, psychologist, nurse, social worker) with whom they were able to establish a good working relationship. It's worth the wait.

My psychiatrist was very supportive. She helped me to balance my life and put things in perspective. It was amazing what a difference that made. SHIRLEY

Education

Proper diagnosis and treatment are essential when dealing with manic depression and depression, but another key part of the picture is education. This is what helps patients to live their lives while they

are recovering. Education also helps family members to better understand and cope with their loved one's illness.

After I got well enough, I attended classes on how to manage bipolar disorders, anxiety and panic. After I got into them, I wished I'd had them 20 years ago. There was so much information. **STEPHEN**

Education and information about mood disorders can come from several sources.

Information sessions

Mood disorder clinics in hospitals sometimes provide information sessions for both patients and families.

Books and other consumer resources

There are many books available that provide a wealth of information about mood disorders. A list of the best ones, selected by patients and professionals, is included at the end of this chapter.

Self-help Groups

One of the surprises for me about support groups was finding out that others had similar experiences. I would not call myself a group kind of person but it really helped me to hear others' experiences and realize you can get better and even stay well. **PENNY**

A chief source of support for people with mood disorders is self-help groups. These are consumer-driven groups that meet weekly, bi-weekly or monthly where people share experiences and support each other. Leadership is shared by volunteers, and the focus is on

living with your condition as opposed to fixing it. Often, people come to the groups when they need a lot of support and then stay on to help others when they are feeling better themselves. These groups help consumers in several ways.

Somebody else understands

If you haven't been a sufferer with these illnesses. If you haven't laid awake at 4 o'clock in the morning wondering about the guy beside you, there are some things that you just won't understand. **DANIELLE**

Some consumers say that although professionals are very knowledgeable about diagnosis and treatment, they can only understand so much because they have not lived the experience themselves.

There are parts of this the doctors just don't get. They don't know what it's like to watch your spouse suffer. They don't know what it's like to keep paying for medication. **ALBERT**

Sharing useful information

Participants in self-help groups often learn from each other's experience and get advice about services that were helpful to others. It's also a place to share information on current events and the latest research.

It was at the self-help group where I first learned about the materials I could borrow from the library at the local depression association, and I met a volunteer who was very helpful in referring me to other sources of help. **SHERRY**

A support network of your own

Many people have reported that the staff and volunteers of self-help organizations helped them in times of crisis.

What I liked about the support group was that your own experience feels validated. You know that somebody else has gone through the same difficulties. **ERIC**

Finding a group

Most communities have self-help groups. Some have self-help resource centres which provide support for groups and help people to find them. To find a self-help resource centre, try looking in the phone book under self-help or contact one of the following organizations:

- Your local chapter of the Canadian Mental Health Association (CMHA)
- Your local Depressive/Manic Depressive or Mood Disorders Association
- The local health unit or public health department
- Your family doctor, mental health professional or the nearest hospital
- Your community information centre (sometimes called Information and referral)

Helping your partner find a group

If you are the spouse of someone with a mood disorder, you might be thinking, "Great! Let's sign him up right now." The difficulty is that if your partner has an affective disorder she may not see things the way you do. So you may find yourself in a situation where you are ready for your partner to go and he may not feel ready himself.

Don't force this issue

You can encourage but, unless someone is ready to make the move, it may be hard to get them to attend a self-help group. You can help by doing the research, finding out where and when the group meets, and perhaps making contact with the leader. But you can't really make your partner attend. That decision rests with him and you must respect his wishes.

I guess everyone needs to do things on their own time. For me, I needed to go as soon as I heard about these groups, but I think my husband needed to feel a little better before he went. I would come home from meetings of the family group and tell him how helpful they were for me. It must have taken about four or five months before he agreed to come to one with a guest speaker. After that we went together, and it was good for both of us. SAMANTHA

Resources

Organizations

The two major support organizations for people with affective disorders are the Canadian Mental Health Association (CMHA) and the Depression and Manic Depression Association or Mood Disorders Association. If you have trouble locating your local office, try contacting the provincial office:

■ Newfoundland

CMHA

Box 5788

St. John's, NF A1C 5X3

(709) 753-8550

Nova Scotia

CMHA

63 King St.

Dartmouth, NS B2Y 2R7

(902) 466-6600

Prince Edward Island

CMHA

178 Fitzroy St., P.O. Box 785

Charlottetown, PEI C1A 7L9

(902) 566-3034

New Brunswick

CMHA

65 Brunswick St.

Fredericton, NB E3B 1G5

(506) 455-5231

Quebec

CMHA

550 Sherbrooke St. W., Suite 2075

Montréal, QC H3A 1B9

(514) 849-3291

L'Association des dépressifs et maniaco-dépressifs

801, rue Sherbrooke est, bureau 301

Montréal, QC H2L 1K7

(514) 529-7552

Ontario

CMHA

180 Dundas St. W., Suite 2301

Toronto, ON M5G 1Z8

(416) 977-5580

- **Mood Disorders Association of Ontario**
40 Orchard View Blvd., Suite 222
Toronto, ON M4R 1B9
(416) 486-8046
- **Manitoba**
CMHA
2 – 836 Ellice Ave.
Winnipeg, MB R3G 0C2
(204) 775-8888
- **Mood Disorders Association of Manitoba**
4 – 1000 Notre Dame Ave.
Winnipeg, MB R3E 0N3
(204) 786-0987
- **Saskatchewan**
CMHA
2702 – 12th Ave.
Regina, SK S4T 1J2
(306) 525-5601
- **Alberta**
CMHA
328 Capital Place, 9707 – 110th St.
Edmonton, AB T5K 2L9
(780) 482-6576
- **Depression and Manic-Depression Association of Alberta**
Box 64064
Edmonton, AB T5H 0X0
1-888-757-7077

- **British Columbia**
CMHA
#1200 – 1111 Melville St.
Vancouver, BC V6E 3V6
(604) 688-3234
- **Mood Disorders Association of British Columbia**
201 – 2730 Commercial Dr.
Vancouver, BC V5N 5P4
(604) 873-0103
- **Northwest Territories**
CMHA
P.O. Box 2580
Yellowknife, NT X1A 2P9
(867) 873-3190
- **Yukon**
CMHA
6 Bates Cres.
Whitehorse, YK Y1A 4T8
(867) 668-8812
- **Depression Hotline: 1-888-557-5051**

Books

Books for Families

- *Affective Disorders and the Family: Assessment and Treatment.* Edited by John Clarkin, Gretchen Haas and Ira Glick; Guilford Press, 1988
- *Coping with Mental Illness in the Family: A Family Guide.* Agnes B. Hatfield; NAMI book #6, 1991
- *Grieving Mental Illness: A Guide for Patients and Their Caregivers.* Virginia Lafond; University of Toronto Press, 1994
- *Helping Your Depressed Child.* Lawrence L. Kerns; Prima Publishing, 1993
- *Hidden Victims, Hidden Healers: An Eight-stage Healing Process for Families and Friends of the Mentally Ill.* Julie Tallard Johnson; Doubleday, 1988
- *How to Live with a Mentally Ill Person: A Handbook of Day to Day Strategies.* Christine Adamec; Wiley, 1996
- *Nothing to Be Ashamed Of: Growing Up with Mental Illness in Your Family.* Sherry H. Dinner; Lee and Shepard Books, 1989
- *On an Even Keel.* Charles Thériault and Léa Chamberlain-Thériault; Leméac, 1994
- *Understanding Your Teenager's Depression: Issues, Insights and Practical Guidance for Parents.* Kathleen McCoy; Perigee Books, 1991
- *Your Brother's Keeper: A Guide for Families Confronting Psychiatric Illness.* James Roy Morrison; Nelson Hall, 1983

Biographies

A Brilliant Madness: Living with Manic Depressive Illness. Patty Duke and G. Hochman; Bantam, 1992

Darkness Visible. William Styron; Random House, 1990

In the Jaws of the Black Dog. John Bentley Mays; Penguin, 1995

On the Edge of Darkness. Kathy Cronkite; Doubleday, 1994

Speaking of Sadness. David Karp; Oxford, 1996

Books for Children of Depressed Parents

Sad Days, Glad Days: A Story About Depression. DeWitt Hamilton; Whitman, 1995

Wish Upon a Star. Pamela Laskin; Imagination Press, 1991

Internet Resources

Health Canada

Child and Youth Mental Health Site

http://www.hc-sc.gc.ca/hppb/childhood-youth/cyfh/child_and_youth/

Health Canada

Mental Health Promotion Site

<http://www.hc-sc.gc.ca/hppb/mentalhealth/>

We value your feedback

The Childhood and Youth Division of Health Canada welcomes your comments or suggestions on the booklet “All Together Now: How families are affected by depression and manic depression.” Please take the time to complete this form and send it by mail, fax or e-mail as indicated below.

Reader Information

Which of the following describes you?

(You may check off more than one category.)

- ☐ Parent/caregiver
- ☐ Spouse
- ☐ Youth (14 to 18)
- ☐ Professional working with a patient with an affective disorder
- ☐ Professional working with a child living in a family with a parent with an affective disorder
- ☐ Service provider to a family with a:
 - ☐ Government organization
 - ☐ non-governmental organization
 - ☐ Other(Please specify):

How did you obtain your copy of All Together Now?

- ☐ I requested a copy
- ☐ I picked it up from a display
- ☐ I received a copy from (Specify organization):
- ☐ I downloaded it from the Internet
- ☐ Someone gave me a copy
- ☐ Other (Please specify):

.....

How would you rate the information contained in All Together Now?

- ☐ Very good
- ☐ Good
- ☐ not very useful
- ☐ not useful

I especially liked:

.....

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I would like to have seen:

.....

.....

.....

I am aware of the following program or resource which would be helpful to a family coping with an affective disorder:

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Please return this form to:

Health Canada
Childhood and Youth Division
Attention: *All Together Now*
Postal Locator 1909C2
Jeanne Mance Building
Ottawa, Ontario K1A 1B4

or forward comments by email to:
childhealth@www.hc-sc.gc.ca

or by fax (613) 954-3358



Although almost everyone will say, "I'm depressed," from time to time, feeling sad or down is not the same as suffering from depression. We know a lot more about depression and manic depression than we did only a few years ago, and we've learned how deeply these disorders affect the whole family. That's why this booklet was written: to help families live with affective disorders. Some of these suggestions may be helpful in your family, or you may just feel better knowing that someone else understands what you're going through.